

# Goals of care at the end of life

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## CME

### ETHICS CME, Part 2 of 3

Target audience: All physicians

#### Learning objectives:

1. List the different goals of care at the end of life and how they interrelate and change.
2. Be able to use the 7-step protocol to negotiate goals of care.
3. Be able to communicate prognosis and its uncertainty.
4. Know how to tell the truth and identify reasonable hope.
5. Be able to use language effectively.
6. Be able to set limits on unreasonable goals.
7. Be able to adjust care and communication according to culture.
8. Identify goals when patients lack capacity.

#### Faculty credentials/disclosure:

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*Before beginning this activity, please read the instructions for CME on p. 214. This page also provides important information on the method of physician participation, estimated time to complete the educational activity, medium used for instruction, and date of release and expiration. The quiz, evaluation form, and certification appear on pp. 214–216.*

This article discusses how to determine and agree on goals of care for a patient nearing the end of life. This topic brings together some of the previous material from the Education for Physicians on End-of-Life Care program. For example, advance directives and pain management are important issues to consider in arriving at goals of care. Frequently, patients and their families do not have advance directives and have not ever discussed end-of-life management. The case study presented below illustrates some of these points.

## CASE STUDY

Ben Worth, an 80-year-old man who was diagnosed with Alzheimer's disease 4 years ago, developed fever and lethargy. He was admitted to the hospital with pneumonia. Because Ben could not understand his illness or articulate his wishes, the physician spoke with his wife, first asking how Ben had been doing at the nursing home. The wife explained that Ben's condition had been

going downhill. He spent most of his time looking out the window, and his speech was repetitive and nonsensical. He could not feed himself, so she was coming at mealtimes to feed him. When the physician asked if she and Ben had ever talked about how he would like to be cared for near the end of his life, she said that they had never discussed it.

The physician then asked: "Have you and your husband ever had a friend or relative who was sick or died in the hospital?" This question brought out a story about the patient's Aunt Sylvia, who had died in the intensive care unit (ICU) after being on a ventilator. The wife said that Ben was adamant that he did not want that to happen to him. He disliked the idea of Sylvia being hooked up to tubes and needles. The physician explained that Sylvia's physicians were trying to keep her alive a little bit longer. "I guess so, but why? Is that living? That's not living, is it?" the wife responded. The physician delved deeper: "Why do you say that's not living?" She explained, "Well, because she was suffering and she didn't understand why." The wife felt sure that Ben would not want to suffer this way.

Based on this discussion and his better understanding of Ben's wishes, the physician stated, "Were Ben to become very ill, he would want us to make him comfortable and not want us to cause him suffering just to keep him alive for a short time." He then suggested care to make Ben comfortable, as well as a "do not resuscitate" order and instructions not to transfer the patient to an ICU. The physician clearly explained what a "do not resuscitate" order meant. After the suggestions, the wife said, "Thank you. I know that's what Ben would want."

## THE INTERRELATIONSHIP OF GOALS OF CARE

All people have goals and hopes and enjoy having control over their lives. Over time, each person develops a very personal sense of what brings greatest meaning and value and adds most to his or her quality of life. People in the hospital often feel that they are losing control. As their illness progresses, their goals and

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**Table 1. Potential goals of care**

- Cure of disease
- Avoidance of premature death
- Maintenance or improvement of function
- Prolongation of life
- Relief of suffering
- Optimized quality of life
- Maintenance of control
- A good death
- Support for families and loved ones

hopes may change. It is the physician's role to communicate with the patient and family, clarify their goals and priorities, and develop a plan of care based on this information. Regular reassessment of goals and priorities ensures that patient, family, physician, and health care team are working together to maximize the patient's quality of life (1).

Some potential goals of care are listed in *Table 1*. Historically, there has been a dichotomous division of goals of care, with a primary focus on curing illness rather than on relieving suffering in the dying patient (2). This is not surprising, given the training of the past few generations of physicians who concentrated on learning about and applying the tremendous advances in scientific medicine. As recently as 1997–1998, only 4 of the 126 US medical schools required a separate end-of-life course in the curriculum (3). Training at the residency level has been lacking as well. In 2000, a JAMA article documented that 50 top-selling textbooks from multiple medical specialties generally offered very little information on caring for patients at the end of life. More than half the textbooks had virtually no content at all (especially texts on surgery, infectious diseases and AIDS, and oncology-hematology) (4). These examples underline the fact that few physicians have received adequate training in end-of-life care. Thus, it is not surprising that many doctors lack confidence and competence in this increasingly important aspect of medicine.

One consequence of the emphasis on curative or life-prolonging therapy is that sometimes treatment is maintained beyond its effectiveness. Then one day the physician abruptly announces to the patient and family that treatment is not working and that the patient is a candidate for hospice care. Under current guidelines, a patient should have a predicted life expectancy of <6 months to qualify for hospice. The average hospice stay in the USA is much shorter, indicating that referrals are made too late. A recent study of 5 hospice programs in Chicago showed that the median survival after referral was only 24 days (5).

Rather than suddenly switching from one goal of care to another, the treatment team should make the shift gradually. Efforts that focus on relieving suffering and improving quality of life for patients with any life-threatening illness can be introduced earlier, even while attempts at cure and life prolongation are ongoing. With increased access to symptom management and supportive care, it is possible that patients will feel better, continue more of their usual lifestyle, and be better able to handle

**Table 2. Seven steps in negotiating goals of care**

1. Create the right setting
2. Determine what the patient and family know
3. Explore what they are expecting or hoping for
4. Suggest realistic goals
5. Respond empathetically
6. Make a plan and follow through
7. Review and revise periodically, as appropriate

their illness and sustain treatment. It should be realized that some goals may be contradictory and that certain goals take precedence over others, depending on the patient's situation.

Palliative care is interdisciplinary; it affirms life and regards dying as a normal process. It seeks to provide relief from pain and other distressing symptoms. Moreover, it attempts to integrate the psychological and spiritual aspects of care. Treatment can begin to focus on palliative care for patients with a life-threatening diagnosis at any time during their illness, whenever they have supportive care needs.

## NEGOTIATING GOALS OF CARE

The 7 steps to negotiating goals of care (*Table 2*) are similar to those recommended in Dr. Robert Buckman's excellent book, *How to Break Bad News* (6). The physician should be careful about making assumptions concerning the patient's and family's understanding of the disease and should explore what they are expecting or hoping for. For patients facing the end of life, it is important that the physician clarify these areas, particularly when there is a conflict between aspirations and what is medically likely or possible. The physician should suggest realistic goals for the situation, showing empathy, which is always to be cultivated. The key issue is to make a plan that everyone agrees to and then to follow through on it. As changes occur, the group should review the plan and revise it if necessary. The original plan may serve the patient well during the entire illness. At other times, a major revision is required because the patient's and family members' goals have changed.

## COMMUNICATING ABOUT PROGNOSIS AND TREATMENT

Predicting the future is an occupation fraught with peril. Determining prognosis for patients near the end of life is also a challenge (7). Christakis and Lamont recently reported physicians' survival estimates for 468 patients at the time of hospice referral. Only 20% of their predictions were accurate (within 33% of actual survival); 63% were overly optimistic, and 17% were overly pessimistic (5). The longer the doctor had cared for the patient, the more overly optimistic the survival prediction tended to be. In the SUPPORT study, physicians also tended to make significant errors in both directions when predicting the life span of patients in the ICU (8). Even if statistics on thousands of patients show a median survival of 3 months, an individual patient may differ. Therefore, it seems preferable to provide a range that encompasses average life expectancy and to stress the quality of that remaining life. Patients and their fami-

**Table 3. Language about palliative care that has negative connotations**

- Do you want us to do everything possible?
- Will you agree to discontinue care?
- It's time we talk about pulling back.
- I think we should stop aggressive therapy.
- I'm going to make it so he won't suffer.

lies need some idea of likely survival time so that they can make necessary plans. However, individual situations vary widely, and it is vital to preserve hope. "Be optimistic but realistic" is a useful approach. Perhaps nowhere is the art of medicine as important as in this context (9). Not too long ago, many patients with cancer were never told their diagnosis, let alone their prognosis (10).

Some physicians who utilize aggressive therapy may have trouble letting go. For example, 3 consultants for a patient in the ICU may agree that the patient is losing ground because of multiorgan failure. Then the attending physician comes by and tells the family, "Your mother's fever is down and she's doing better." Such communication confuses the family and is not realistic. False hope can deflect from other important issues. Clinicians should communicate with each other and with other members of the health care team to help patients and their families find hope for realistic goals.

The language chosen in communicating about treatment is important. Well-intentioned clinicians may say things that have unintended consequences or negative connotations. Compare the statements in *Table 3* with those in *Table 4*: statements in the first group focus on withdrawing treatment, while those in the second group emphasize supporting the patient and fulfilling his or her desires.

Cultural differences must be factored into communication as well. Culture affects decisions about who receives the information, how the information is discussed, and how treatment decisions are made. Family meetings may be an option when no single spokesperson has been named. It is important to ensure continuity and avoid situations in which different family members are speaking to different physicians but not sharing the information with each other or with other family members.

Goals for care should guide the treatment that patients and families choose and receive. In addition to helping them establish overall goals, physicians can assist patients and families in clarifying priorities for care.

### SETTING LIMITS ON UNREASONABLE GOALS

What happens when the physician cannot support a patient's or family member's choice? This typically occurs when the goals are unreasonable or illegal. In this case, the physician should make the conflict explicit, set limits without implying abandonment, and try to find an alternative solution.

I faced such a situation several years ago when asked by another physician to assume the care of a woman with advanced myeloma. Her disease was refractory to therapy and it was unlikely she was going to improve. Nevertheless, her quality of life

**Table 4. Language about palliative care that has more positive connotations**

- I'm going to give the best care possible until the day you die.
- We will concentrate on improving the quality of your child's life.
- We want to help you live meaningfully in the time you have left.
- I'll do everything I can to help you maintain your independence.
- I want to ensure that your father receives the kind of treatment he wants.
- Your child's comfort and dignity will be my top priority.
- I will focus my efforts on treating your symptoms.
- Let's discuss what we can do to fulfill your wish to stay at home.
- Let's discuss what we can do to have your child die at home.

and ability to interact with family and friends were, by her own estimation, relatively good. Her husband was convinced she was suffering needlessly and asked me to kill her. He persisted despite her report to multiple physicians and nurses that she was comfortable most of the time. I explained that active euthanasia was illegal under current law and that I would not fulfill his request. After the woman died, her husband became involved in lobbying efforts to persuade the Texas legislature to enact a physician-assisted suicide law similar to the one in place in Oregon.

At other times, the opposite situation occurs: family members demand treatment that the physician considers futile. A prominent example of this occurred in New Zealand several years ago. The elderly chief of a Maori tribe had been on dialysis for several years and developed dementia. Nephrologists and ethicists from New Zealand, as well as experts from Australia and England, argued that the patient should be removed from dialysis since continued treatment was futile. From their cultural standpoint, members of the Maori tribe vociferously opposed what they considered to be murder of their leader.

The concept of medical futility is indeed difficult (11). There have been many attempts to define medical futility, with a significant amount of controversy in both the literature and in medical practice. Empirical assessments of futility have been inadequate to date. Furthermore, although a large segment of our society continues to use the concept, in practice physicians and patients can't always agree on futility. For example, in the so-called "right to die" cases such as the Quinlan and Cruzan cases, families argued that ongoing life support for their daughters who were in a persistent vegetative state was qualitatively futile. Treating physicians disagreed. Alternatively, in the case of Wanglie (another patient in persistent vegetative state), physicians argued that ongoing treatment was futile, but the family wanted all treatments continued. Currently, we tend to refer to cases in which the patient or family requests withdrawal of life-sustaining treatment as "right-to-die" cases, and we tend to refer to those cases in which the physicians and nurses recommend withdrawal of life-sustaining treatment as "medical futility" cases. The thoughtful practitioner will recognize that these are two sides of the same coin.

Of the various definitions proposed for futility, two general concepts seem to be emerging. The first is "physiologic futility,"

the most objective standard. An example might be to say that cardiopulmonary resuscitation for a patient who is exsanguinating is physiologically futile, because for such a patient, only stopping the bleeding and replacing the lost blood has the possibility of saving the patient's life. The second concept is that of "qualitative futility," the more subjective standard. For example, most parties argue that it is qualitatively futile to provide life-sustaining therapies to a patient who is either brain dead or in persistent vegetative state, even though it is not necessarily physiologically futile to do so.

Despite these inherent difficulties, the Texas legislature has recently enacted a law that specifies a process to deal with disputes between providers and patients or families over the provision of life-sustaining treatments. This process is as follows:

- The family must be given written information concerning hospital policy on the ethics consultation process.
- The family must be given 48 hours' notice and be invited to participate in the ethics consultation process.
- The ethics consultation team must provide the family with a written report of the findings of the ethics review process.
- If the ethics consultation process fails to resolve the dispute, the hospital, working with the family, must try to arrange transfer to another provider physician and institution who are willing to give the treatment requested by the family and refused by the current treatment team.
- If after 10 days, no such provider can be found, the hospital and physician may unilaterally withhold or withdraw the therapy that has been determined to be futile.
- The party who disagrees may appeal to the relevant state court and ask the judge to grant an extension of time before treatment is withdrawn. If the family does not seek an extension, or if the judge fails to grant one, futile treatment may be unilaterally withdrawn by the treatment team with immunity from civil or criminal prosecution.

This practical approach, described in more detail elsewhere, represents an important advance in developing a workable process to settle disputes over medical futility (12).

## IDENTIFYING GOALS WHEN PATIENTS LACK CAPACITY

For patients to make medical decisions for themselves, they need to understand the situation, be rational, and appreciate the consequences. Usually any physician can determine decision-making capacity; it does not require a psychiatrist or a court rul-

ing. A patient may be capable of making medical decisions but not other decisions (e.g., legal, financial).

If a patient is incapable of making decisions, the physician should first see if a proxy has been named, i.e., whether medical power of attorney has been designated. Generally the proxy is selected because the patient feels that person is most likely to know what he or she wants. The proxy may be the spouse, a relative, or a family friend. Secondly, the physician should determine whether the patient has given an advance directive.

When no proxy or advanced directives can be identified, the physician can rely on different sources of information on the patient's desires: the patient's verbal statements, general values and beliefs, how the patient lived his or her life, as well as determinations of what is in the patient's best interests. Generally, the physician will need to talk to family members and friends to get an idea of the patient's values, as illustrated in the case study. However, this information is basically a guess. It is far better to discuss medical power of attorney and advance directives with the patient early in the disease process so that the likelihood of fulfilling the patient's wishes and preferences can be maximized.

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